

The University of Technology Sydney

A thesis submitted in fulfilment of the degree of
Doctor of Philosophy

**Help-seeking Behaviour of Chinese
Carers of People Living with Dementia**

Siu-Wan Lisa WONG

2019

CERTIFICATE OF ORIGINAL AUTHORSHIP

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Production Note:

Signature removed prior to publication.

Signature of Student

Date: 28th January 2019

ACKNOWLEDGEMENTS

I would like to thank all the participants in this study, for their courage and genuineness in sharing their experience in seeking help for their family member with/without a confirmed diagnosis of dementia.

I would like to dedicate this thesis to my elderly parents Yuen Ming Wong and Shou Kum Wan, for their endless love and support throughout all these years, in particular to my father and my family who has to look after my mother with moderate grade of dementia. This thesis is also dedicated to people living with dementia and their family, and the memory of those who went before, with respect for their courage in living to the fullest.

I would like to give my sincere thanks to Emeritus Professor Jane Stein-Parbury and Professor Lynnette Chenoweth, for their enlightenment, astute supervision and unfailing support throughout the last seven years. I would also like to thank Professor Michelle DiGiacomo for her advice and contribution during the last two years of my study.

I would like to thank Dr. Catherine Heath for her professional help in copyediting my thesis. I thank my fellow postgraduate students for their support and comments.

ABSTRACT

Background: The challenge of caring for a family member with dementia is exacerbated when carers do not seek support from others. The aims of the study were to explore: the socio-cultural factors involved in Chinese carers seeking or not seeking help with the care of a family member with dementia, and the enablers and the barriers to help-seeking in the caring role.

Method: This exploratory, qualitative investigation employed semi-structured interviews with 16 Chinese people caring for a family member with symptoms of dementia. Nine participants sought help, and seven had not sought help.

Results: Chinese cultural ideology influenced perceptions of caring responsibilities and help-seeking decisions in both groups. Barriers included: misinformation from medical practitioners, lack of information about and confidence in support services, and reluctance to seek help. Enablers included: acceptance of dementia, acknowledgement of the need for support, and availability of Chinese dementia support services.

Conclusion: Maintaining Confucian social order, including protection of family honour, veneration of elders and filial piety, influence help-seeking as well as access to culturally sensitive and safe support services. These findings have the potential to improve service utilization and opportunities for Chinese carers by informing improved outreach and educational services that accommodate Chinese cultural beliefs and practices.

TABLE OF CONTENTS

Certification of original authorship	ii
Acknowledgements	iii
Abstract	iv
List of Figures and Tables	xiii
CHAPTER 1: INTRODUCTION	1
Caring for people with dementia	4
My interest in this study	5
Study Overview	8
Organisation of thesis	8
Glossary of Terms and Abbreviations	10
CHAPTER 2: BACKGROUND: THE CHINESE CULTURE	11
Introduction	11
Chinese Tradition and Values	11
Veneration of elders and filial piety	14
Fatalism in Chinese culture	15
Stigmas and stereotypes in Chinese culture	18
Chinese and Western Cultures	19
Conclusion	23
CHAPTER 3: LITERATURE REVIEW: HELP-SEEKING	25

Introduction	25
Literature Search Strategy	25
Literature in English	26
Search terms in simplified and traditional Chinese	28
The Process of Help-seeking	30
Help-seeking in Dementia	32
Diagnosis in dementia	34
Attributions about changes in cognition, mood and behaviour	35
Delay in help-seeking	37
Misattribution of dementia symptoms	37
Stigma	39
Reasons to seek help	41
Help-seeking in culturally diverse populations	42
Barriers in help-seeking	42
Enablers in help-seeking	45
Help-seeking in Chinese populations	47
Limitations of help-seeking in dementia research	51
Conclusion	53
CHAPTER 4: METHODS	55
Study Aims	55

Conceptual Framework	55
Help-seeking	56
Influence of Culture	56
Study Design	57
Setting and participants	58
Participant inclusion criteria	58
Participant exclusion criteria	59
Sampling	59
Participant recruitment	59
Ethical considerations	61
Ethics approval	62
Voluntary participation	62
Informed consent	64
Respect	64
Confidentiality	65
Potential risks	65
Potential benefits	67
Data Collection	67
Data management	71
Reflexivity	73

Self-reflection of potential bias	76
Data Analysis	80
Summary	81
CHAPTER 5: RESULTS	82
Introduction	82
Description of Participants	83
Help-seeking carers	83
Non-help-seeking carers	84
Influences on Help-seeking	85
Culture	87
Cultural ideology	87
Protection of family honour	87
Veneration of elders	88
Saving face	88
Filial piety	89
Fatalism	90
Cultural practices	90
Gender role and responsibilities	91
Health traditions and customs	91
Perceptions of illness	93

Awareness of symptoms	93
Memory loss	94
Changes in mood and behaviour	96
Apathy and lack of motivation	96
Meaning attributed to symptoms	97
The ageing process	98
Mood changes in ageing	99
Specific health issues	100
Views about help	101
Barriers to help-seeking	101
Poor knowledge of dementia	102
Misinformation from medical practitioners	103
Lack of information about services	104
Reluctance to access services	104
Complexity of carer support access	105
Lack of confidence in services	106
Enablers to help-seeking	106
Knowledge and acceptance of dementia	107
Acknowledgement of need for support	108
Availability and access to Chinese support service	109

Information from support network	110
Expectations of help-seeking	112
Seeking a cure	113
Resolution of behavioural issues	113
Support to reduce carer stress	114
Support with caregiving responsibilities	114
Summary	116
CHAPTER 6: DISCUSSION	118
Introduction	118
Maintenance of Social Order	119
Obligation to family	119
Protection of family honour	120
Face-saving	120
Hierarchical relationships	121
Veneration of elders and filial piety	122
Gender roles	123
Gendered values and help-seeking	124
Chinese Tradition and Folklore	127
Fatalism	127
Dementia as social stigma	128

Retention of Cultural Values and Identity after Migration	128
Traditional Chinese health customs	129
Adaptation to a new environment	131
Motivation in acquiring knowledge	132
Availability of Culturally-specific Support Services	134
Lack of culturally-specific information	135
Translation and interpretation services	137
Implications and Recommendations	137
Strengths and Limitations of the Study	144
Conclusion	147
LIST of APPENDICES	149
Appendix A: Information Sheet	150
Appendix B: Information Sheet in Chinese	152
Appendix C: Information Sheet in Chinese	154
Appendix D: Consent Form- Help-seekers in Chinese	156
Appendix E: Consent Form- Non-help-seekers in English	158
Appendix F: Consent Form- Non-help-seekers in Chinese	160
REFERENCES	162

List of Figures and Tables

Figure 3.1: Literature search in English	27
Figure 3.2: Literature search in Chinese	29
Table 3.1: Interview Schedule	69
Table 4.1: Demographics of help-seekers	83
Table 4.2: Demographics of non-help-seekers	84
Table 4.3: Factors influencing help-seeking	86
Figure 4.1: Central aspects of cultural ideology	87
Figure 4.2: Central aspects of cultural practices	91
Figure 4.3: Symptoms that were noticed	94
Figure 4.4: Attribution of symptoms	98
Figure 4.5: Barriers to help-seeking	102
Figure 4.6: Enablers of help-seeking	107
Figure 4.7: Expectations of help-seeking	112